

Personal assistance as key to Independent Living

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Introduction

Social policy is typically not made by the people who are most affected by it. Up to now, we, the users of assistance, have had to accept the decisions handed down to us by other people. Since we are often considered helpless and incapable of taking charge of our own lives, the public and often we ourselves have taken for granted that it is best for us, if others, the professionals make these decisions for us.

In 1992, the inner market of the European Community will become reality. In preparing for this date politicians and experts are now working on how to harmonize most areas of life within the European Community. Those of us not living in EC countries will most likely be affected too by this move. Harmonization efforts are also on their way in the area of social policy. For us this is both a danger and an opportunity. Once more we face the risk that important decisions are made without our input. But we still have time to make our voices heard. We still can put our minds together and work out a common platform with which we can influence decision makers both in our respective countries and on the European Community level.

Expected outcomes of this conference

One of the outcomes of these three days will hopefully be a document that outlines the basic ingredients of personal assistance schemes which empower us and get us closer to the goal of full participation and equal opportunities.

We also need to agree on how to best use the document in our dealings with national governments and European Community authorities.

We should also develop a plan on how we can continue the present effort and work together on improving personal assistance services. We should not consider the present meeting as an isolated event but as the beginning of a series of recurring meetings and joint projects. If we want to reach our goal and improve our quality of life through personal assistance, we have to be prepared to work systematically, concentrated and step by step over a long time.

The present conference was conceived and planned by several individuals who represent different groups. Apart from the formal organizers, the Greens, there were also people from the international Independent Living Movement. There exists now an attempt to organize a world-wide network of groups and individuals subscribing to the Independent Living ideology, a network that would work within DPI, Disabled Peoples' International. We would like to look at this conference as the first project of this new Independent Living network. The purpose of this network is to speed up the Independent Living Movement's expansion throughout the world.

What is the philosophy of the Independent Living Movement and what are its aims?

Anti-discrimination

The Movement works against the discrimination of people with disabilities and for more personal and political power. Everywhere people with disabilities as a group are disadvantaged in education, work, income, housing, transportation, in family life, in the social, political and economic lives of our communities. Some of us do not even get a chance to live, because they are killed before they are born. The more practical assistance we need, the worse is the discrimination we are exposed to. One of our goals is to introduce legislation in all countries, that makes it illegal to discriminate against anybody on the basis of disability.

De-medicalization

One of the reasons why we are discriminated against is that we deviate from what people think is "normal". Society has a tendency to label people who are different as "sick". Sick people do not have to work, are exempted from the normal duties of life, and are marginalized. As long as we are considered sick by the general public, there will be little understanding, for example, why we want to use regular public transportation and are not satisfied to go by ambulance. One of our main goals is to make clear to our communities and to ourselves the difference between being sick and being healthy, normal citizens with disabilities who have the same rights to the good life as everybody else.

De-institutionalization

Since we are often considered sick, many of us get shut away in hospitals and hospital-like institutions. There, it is claimed, we can be better "cared for". With this argument we are put into special kindergartens, special schools, special workshops, special housing and special transportation. The only places that are still not segregated are the cemeteries! We have to shut down these special, dehumanizing and degrading Apartheid solutions and force our way into the mainstream of society.

De-professionalization

Many people think of us as sick people who have to be "cured" or at least "rehabilitated". Many believe that we need special, tender loving care by lots of people in white coats. The more disabled we are, the sicker we are in the eyes of our surroundings and the more professional training the people need who are charged with the task of taking care of us. In this way, society has handed over to the professionals control over our lives. Many of us have been raised in the belief that a medical doctor or a social worker is best qualified to make decisions regarding our lives. The more power we attribute to the person in the white coat, the less we believe in our own strength. It is time that we come to a realistic assessment of what other people can do for us and what we can do for ourselves. It is time that we take back the power we have handed over to the professionals.

Control over our organizations

Do we have organizations **for** disabled people or **of** disabled people? Are non-disabled professionals in control who look upon disabled people as clients? Or are people in charge who themselves know what it is like to be part of an oppressed minority, people who are fighting for their own rights? This does not only apply to the board, we also need the staff positions where the day-to-day decisions are made. At the present unemployment among our people we need the work and training opportunities that our organizations provide. Society looks upon us as helpless people who cannot speak for themselves. If we allow non-disabled people in our own organizations to speak on behalf of us, we are confirming these prejudices. What would the public think about a women's liberation group with mainly men in the office?

We need the coalition with non-disabled friends in our fight for equal rights. But if our friends really understand our cause, they will step down from important positions within our organizations.

Self-management of our services

Another reason why we need people with disabilities as staff in our organizations is that we are the best experts on our needs. Services, such as transportation or assistance are typically designed, controlled and run by non-disabled professionals. These people, however well-intentioned they may be, simply cannot have the insight in our needs, life-styles and aspirations which we have. As a result we see paratransit systems that run Monday through Friday, as if we had no need to leave our homes on weekends. We see personal assistance schemes that provide services only within the political boundaries of our communities, as if we never had the need to cross city limits. If we leave design and control over such services to other people, we should not be surprised, if they come up with solutions which fit the needs of their existing bureaucracies instead of our needs.

We have a choice: we can go on feeling as powerless victims, as victims of other people's insensitivity, lack of understanding, conspiracy or whatever. Or we can choose to feel in control of our life and take charge of it. If we don't want to play the role of the victim, we have to take the initiative in the political and practical work of designing our key services ourselves.

Peer counselling

Independent Living is really basic applied psychology. The most important change we have to make is the change within ourselves. We do not need to wait until other people get around to changing their attitudes against us. When we look at ourselves differently, other people too will see us in a different light. When we respect ourselves as citizens with equal rights, it will be easier for us to convince others that we indeed have equal rights.

To change one's perception of oneself is difficult. There are times when we need to talk with people we can identify with because they are or have been in a similar situation. The example of such a person is a much more powerful help than the best advice of a non-disabled expert. The Independent Living Movement utilizes this principle in a systematic fashion. We call it peer counselling. Peer counselling means to share the fruits of one's experience. It is our foremost educational tool to empower each other by exchanging practical information, personal experiences and insights and by raising our consciousness about our role in society and what it takes to liberate ourselves.

Networking

In providing examples for each other and in sharing our experiences we need each other. We all are in the same situation, we all face oppression in our society. Once we realize this, it is only a small step to see that we have to support each other, that we must band together to fight the system and together make this a better world. All of us here probably have had this fundamental experience that all you need is to get together a bunch of crips and politicians will listen - provided you play your cards right. Each of us can profit from joining in. Only together can we gain political power. That is the only power to move things. For this reason we have to organize ourselves.

One of the strengths of the Independent Living Movement, as I see it, has been a lack of interest in building hierarchical national organizations with local chapters. Instead there are groups and initiatives who work on the local level with concrete needs. Each such local organization is independent from each other. When the need arises, flexible coalitions around single issues can be formed. What is most important though is that these local groups or initiatives see themselves as part in a network, a network for the exchange of ideas, technical support and training.

Such a network around personal assistance, I hope, will be one of the outcomes of our present meeting.

What is "personal assistance"?

First of all, everybody uses assistance. Nowadays, we all are dependent on each other. Nobody can perform all the tasks necessary to sustain his life-style. So, people instead of fixing their own car take it to a mechanic. Most people do not know enough about cars or do not have the time. By utilizing somebody else's knowledge and resources we can compensate our lack of ability or lack of time. People like to specialize in doing what they are good at. Most other things they delegate to somebody else. In this way one can be more efficient in the sense that one gets more done.

"Personal assistance" then means that we compensate our disabilities by delegating tasks to other persons. These tasks involve activities which we cannot carry out ourselves or which we are not good at. We delegate in order to have the time and energy to specialize in those activities which we can perform well. "Personal" connotes that the assistance has to be customized to my individual needs. "Personal" also means that the user decides what activities are to be delegated, to whom and when and how the tasks are to be carried out. I think in a world of personal computers and personal telephones the term "personal assistance" is quite descriptive.

What are the alternatives to "personal assistance"? In English, the terms "attendants", "personal care attendants", "carer", "home help", etc are used. Most of these words contain the word "care". To me this word carries the connotation of taking care of somebody who cannot take care of himself or herself. The relationship between "carer" and "caree" implied by this term is not one of voluntary association for mutual gain, it does not clearly state that the "caree" is the one who decides what has to be done. The term "home helper" indicates that "help" is to support activities only in one's home as opposed to a lot of other places such as at work, on the bus, at one's friends' house, etc.

If we want to design services which get us closer to the goal of equal opportunities, we have to find expressions for these services which portray us as responsible and capable citizens who are in command of their lives and not as passive objects. I hope we pay attention to the language we use in describing these services during the next days. Language both influences and reveals attitudes including our own attitudes towards ourselves. I also hope that our interpreters can translate these terms as literally and accurately as possible.

In what forms has assistance been available so far?

Family as assistance provider

The most common form is the family. Reliance on the family may work for some time but the limitations - even under the best of circumstances - are given. Family members get older, they are risking their health in assisting us. Children often have to take too much responsibility too early in their lives. Adults cannot pursue their career and feel locked in. The results are relationships of mutual dependence, sacrifice and guilt. Where guilt is often mistaken for love.

Facing the alternative which often is institutional placement of the disabled family member most families hold out as long as they can - often without any outside assistance - burdened by immense physical, financial and emotional strain.

Volunteers

In some places families get help from volunteers. The virtues of volunteerism are most often praised by conservative politicians whose motives are to cut taxes for the benefit of their voters. Obviously, users of assistance from volunteers cannot demand the same competent, punctual, and courteous work from volunteers as they might from assistants who are paid competitive wages. But in most instances users do not have that choice.

Stationary institutions

The alternative that most of us in Europe have is to live in some sort of institution. Institutions are administrative entities and as such are governed by the necessities of administering buildings, workers and inmates within the boundaries given by budget, labor unions, and state regulatory agencies. These constraints are expressed in a multitude of rules which cannot be adapted to the needs of each individual. Otherwise there would be chaos. As a result, a certain order has to be maintained to guarantee the smooth functioning of the whole. The individual's challenge, then, is to adapt himself or herself to the existing order both physically and psychologically without losing one's integrity as a human being. That is very difficult. One of the survival strategies is to develop a pleasing personality with which you can achieve privileges at the expense of other inmates who are not as adaptable.

The general results of institutional living are known as "hospitalism", that is loss of social skills, foregone life opportunities, and stunted human growth. The problem we are facing in helping people who have been staying in institutions is that they often have lost their self-confidence and are frightened by the prospect of leaving their secure confinement.

A definition of an institution

Perhaps it is appropriate at this point to attempt a definition of an institution. I suggest that we face an institution if

- there is no other alternative,
- other people determine who is to assist us with what functions,
- the user has to adapt his needs to the needs of the whole scheme,
- there are written and unwritten rules regulating the assistance,
- rule over which the user has no control,
- the assistance is limited to certain hours, activities, locations
- (that is you have to live in certain houses as opposed to anywhere),
- the staff providing assistance is shared by several persons,
- there is a hierarchy with the individual user at the bottom of the pyramid.

If we accept this definition as a list of institutional characteristics, then most forms of assistance fall under this category.

Mobile institutions

Take community-based public services. In most of these schemes a caseworker at the municipal social service department assesses your needs and sends workers into your home. Tasks and hours are well defined. Hiring, training and scheduling of the workers is done by the supervisor. These services constitute a tremendous advantage over institutional placement. But you as the user are not in control, you share assistants whom you cannot choose or train yourself. As a result, you are made dependent on other persons' judgement and have to limit your life. You might even limit the use of this type of service to the absolute minimum, because the quality is so low.

False independence

Those of us who need assistance are used to restricted lives. For one, most of us have been exposed to the present rehabilitation philosophy which wants us to do as much for ourselves as we possibly can and even more. "Push your limits, try harder. Exercise, exercise. Don't get lazy, use your manual and not your power wheelchair. "

Our first goal, according to rehabilitation professionals, is to be independent and manage with a minimum of technical aids. Personal assistance should only be used as a very last resort, since it is a recognition of failure on the part of the professionals and ourselves. Or have any of us been taught by a rehabilitation specialist how to delegate tasks to other people? Many of us have accepted these professional priorities. Their purpose in life seems to get out of bed by themselves, get washed and dressed, to cook and clean. Never mind that it takes the whole morning. Never mind that they get so worn out that they have to rest the other half of the day to recover enough strength for going to bed. They may not have a job, they may not be able to do much outside the home, they may not have time and energy to get involved in disability politics and fight for equal rights. But they are proud of being independent.

This narrow definition of independence is reinforced by society around us. "Good boy, look how hard he is trying!" Politicians and administrators like to see us try hard, since they save money on us this way. Personal assistance is expensive. But what a narrow definition of costs this is! What about the time and energy these people could use for other achievements, if they allowed themselves to use personal assistance!

Medical evidence in recent years shows that many of us overexert their remaining muscles, nerve cells and ligaments. As a result they wear themselves out before their time. Too much exercise may cause irreparable damage. The harder we try, the faster we go downhill.

The brainwashing that many of us receive in the process of rehabilitation distracts us often effectively from painful comparisons with other people, our non-disabled friends, relatives and neighbors. How often do we allow ourselves to compare our lives with theirs? It can be painful to admit to oneself that we too would like to have a good job, a nice home and a family. But for many of us these things will be out of reach forever, if we do not have the possibility of delegating practical tasks to personal assistants. Ultimately, it is a question of self-respect. If we respect ourselves as persons of equal value, then we expect and demand the same lifestyle that others take for granted. Then, we will also want to use personal assistance as one of the tools to achieve these goals.

I would like to use an analogy. An entrepreneur or administrator will realize that he or she alone can get done only so much. By employing other persons the entrepreneur can delegate work and in this way increase the total output. Would it be wise for a factory owner to try to do everything all by himself? Most likely such a person would either die of exhaustion or be out of business pretty fast. If entrepreneurs and administrators are not ashamed to utilize manpower to achieve their goals why should we hesitate to do the same?

Empowerment

I started out with the Independent Living philosophy. I hope we keep the elements of this philosophy in mind when we discuss personal assistance services during the next days. The most important element of this philosophy in my mind is empowerment.

Empowerment means to have personal assistance schemes that guarantee us the same degree of geographical and social mobility that other people enjoy. This includes choice of residence, work opportunities, travel, to have a family of our own, to run for political office, etc.

Empowerment means that we can customize individual solutions according to our individual needs which may change over time.

Empowerment means to have access to several different solutions at the same time.

Empowerment means to take individual control over the funds for paying wages and administrative costs.

Empowerment means to organize personal assistance users into a pressure group which negotiates with governmental bodies. Together we have political power, individually we have none.

Empowerment means to help and teach each other through peer counselling the skills it takes to run one's own personal assistance scheme and get the most use out of it.

Empowerment means to devise ways to allow all of us, regardless of physical or mental disability, to take more responsibility over our lives.

I hope that through this conference we will empower ourselves.